

Alzheimer's Disease Working Group Listening Sessions

Between March 31 and May 1, 2015, the Alzheimer's Disease Working Group (ADWG) held seven community meetings as opportunities to hear input from the public. The community meetings were publicized by ADWG members and by DSHS in press releases throughout the state.

Included below are the comments shared by participants during these sessions. The responses are organized by the questions posed and broken down by location.

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ADWG Attendees

- Yakima (3/31/15) – Bob LeRoy, Debbie Hunter, Nelly Prieto, Luisa Parada Estrada
- Seattle (4/1/15) – Bob LeRoy, Chris Henderson, Marty Richards, Dave Budd, Tatiana Sadak, Emma Medicine White Crow, Maureen Linehan, Basia Belza
- Spokane (4/8/15) – Joel Loiacona, Bob LeRoy
- Tribal IPAC (4/14/15) – David Maltman, Bob LeRoy
- Lacey (4/21/15) – Bill Moss, Bob LeRoy, Peggy Quan, Jerry Reilly, David Maltman
- Virtual Session (4/28/15) – Bob LeRoy, Tom Montine, Todd Larson
- Sequim (4/28/15) – Bob LeRoy, Rep. Steve Tharinger, Kathy Moio

General Comments

Yakima

- Family caregiver support coordinator for local AAA. Thoughts for ways to address dementia include In-home coaching models like Star-C. One on one model. Also models such as NY – nursing homes with overnight activity programs for people with dementia (often don't sleep at night) – provides some respite for the caregiver; patient then may sleep some during the day as well.
- Local support group that Kathy leads – important for caregivers. 'Extended long care' – extended care people are not very knowledgeable about caring for PWDs. Dementia training should be a large part of training for professionals like CNAs and other healthcare workers. Doctors also need a lot of training. Even when they can diagnose they often don't know what to do next. They should be trained or have staff who are trained. Also – finding money via federal grants to fund dementia care needs?
- More family caregiver support – in WA there is a program called Community First Choice; provides better federal match for the state. Goes to LTSS, specifically pre-Medicaid, options counseling etc. Wasn't in House budget; isn't in Senate budget that just came out today. There is a significant need for an infusion of additional \$ for family caregiver education and support. Only reaching about 1% of the unpaid family caregivers in WA state. Advocacy is needed with the state legislature as well as with the feds.
- What is available right now for assistance to families who keep their loved ones at home? A: If doing w/o Medicaid, Family Caregiver Support Program/ADRC is good place to start. TCARE – creating a program that is specific to caregiver needs. Help family to grasp the fact that they are caregivers, and help them develop caregiver skills. Meals on Wheels, respite program, classes for caregivers, counseling, etc. Little or no cost to caregivers. A: Alzheimer's Assn programs and services including 24/7 Helpline; please take flyers.
- Was a caregiver for about 5 years; had no idea of available services. How can the word get out to people who don't know about the services? A: had not heard of resources; doctor tried to help; part of the state plan needs to be that doctors have the information to give to families. Q: Local support group(s)? A: Yes – information is available on the alzwa.org, and ADRC.
- Safety was an issue for her family; choosing between what's best for husband (diagnosed with younger onset in his 40s) vs. what's best for the children. Ended up putting husband in a facility because it was the best thing for her kids. The state plan cannot have an age limit on it. Alzheimer's is not just a disease of old age.
- Another issue: Legal aspects of Alzheimer's – exploitation. "Replacement windows" contract signed by wife with dementia. Competency; can PWDs sign contracts? Where do you go for help on this? Consumer Protection Division at state Attorney General's Office. Get power of attorney ASAP when diagnosed. Part of pre-planning while the PWD is still able to participate in the decision process. See theconversationproject.org

- How much should the PWD be told about their disease as the disease progresses? In some situations it can be beneficial. A: Person-centered service planning is a concept that comes from the developmental disabilities community; parallels to dementia.

Seattle

- Trying to get a diagnosis took over a year and wasn't much fun.
- President of the Hearing Loss Association of WA – first time attending, DT usually comes but is ill today. I am deaf and uses cochlear implants. Encourages ADWG to include hearing loss as we discuss aging and cognitive decline. Older people with hearing loss tend to be treated as if they are cognitively impaired. People in long-term care with untreated hearing loss can exhibit behavioral problems. Communication skills in people with cognitive decline parallels communication skills in people with hearing loss.
- Professor at UW – head of Audiology. Also a neuroscientist. Studies on how the brain ages. Her key specialty is understanding the effects of hearing loss on the brain. Supports the recommendations made by Hearing Loss Association. Impact of hearing loss on quality of life is significant. Evidence suggests that hearing loss is a risk factor for dementia. Many of the tools used to diagnose dementia require hearing.
- Is the daughter of a woman with dementia. Her mom has dementia but probably not Alzheimer's. Alzheimer's Association support groups have been very helpful. Concern is how the marketing of the plan does it get to be all inclusive, including other forms of dementia? A: "Alzheimer's Association" includes all related dementias. Always considering the other forms of dementia, but Alzheimer's disease is the most common/prominent form of dementia. There may be a diagnostic difference, but in other respects, such as support and services, the approach will be the same.
- MB is the education coordinator at the Alzheimer's Association Western & Central WA chapter, and is also, in a personal capacity, a member of the Hearing Loss Association.
- Works at Deaf/Blind Service Center, with deaf and blind senior citizens. A small number of the people she works with have dementia. She has some experience with their sequence (?) and partners. Some individuals have had to watch/hover individuals. Explaining about medicine. Saw issues arise. Agrees with Karen Utter that technology is wonderful. When it comes to diagnosis it can be a challenge with deaf individuals. An interpreter can give away an answer with a physician. Was able to volunteer for an experimental project in one of the senior citizen conferences held by a research group at Gallaudet University. Went thru the testing first-hand. Purpose of the research was to test the reliability and cultural relevance of the test. Hopes that the test is usable. The more English-oriented we are, the better able to respond. For individuals who are educationally deprived, they can't respond as well and it skews the results.
- From Asian Counseling and Referral Services – case manager. One of the issues that they come across is that they have a specific evaluation tool for assessing number of care hours needed; dementia isn't reflected in the assessment tool and so PWDs may not get the number of care hours they really need. Another issue is the limited number of resources for people who don't have English as their first language.
- AAA/FCSP in Snohomish County. The assessment tool there has yet to be translated; the state needs to address this ASAP. From the AAA POV – we have a family caregiver

support program that serves ~350 people per year. Other services as well, including geriatric mental health. Partners with Alzheimer's Association; pushing the 800 number (Alzheimer's Helpline?). A big concern is PWDs who don't have family caregivers. Diagnosis can be difficult; the understanding of geriatric mental health issues is probably equal to docs who don't know about the Alzheimer's Association. Community education - there is a great need for a strata of education from basic to more specialized. Move the community to an informed community; an informed community is more likely to use services.

Spokane

- Personally has hearing loss & has felt that professionals feel he is incompetent because he cannot hear what they may be communicating. He read an article on the relationship of AD & the HOH community and feels people with HOH are not being communicated to properly. How does the system accommodate them? Is the delayed speech/response related to AD? People have insinuated he's incompetent due to his lag time in responding.
- With increasing number of people with AD, there's going to be a remarkable increase in numbers of people with dementia being "locked up". PWDs need to get out of lock-up when it is no longer required, especially when it is no longer in their best interest.
- Concerned about how many people in the planning committee even know about the working group. Says people "talk over" the PWD and support is seemingly given more to families than them. In Spokane, when they're in a secure unit – few take Medicaid and many are "lost" resulting in them getting put into an environment that is < ideal. There's a need for increased staffing so we can decrease drug usage. Diagnostics – feels MDs don't talk directly to PWD. Executive function decreases and they don't have sufficient people address the increasing number of issues – we need more trained personnel.
- She is the daughter & d-in-law of PWD who has succumbed to AD. There's one attorney on the working group but not just any attorney will do – elder law attorney is necessary because they approach things from a social standpoint. Finances are a burden so attorneys working with Medicaid benefits become salient to protect assets and provide for the partner at home. All planning needs to happen in the early stage due to the capacity for signature being low anytime beyond that. End of Life issues need to be memorialized for the PWD. It's better to have someone that you name as POA than to have someone appointed. There are laws punishing exploiters and abusers of the elderly that need to be shored up. Support for the Alzheimer's Association is not mentioned in the plan and it should be.
- Down's Syndrome incidence with AD are increasing due to living longer. Detection is hard – how is the working group addressing the issues of diagnostics with Down's? How is the working group addressing the special attention that the Down's family needs since it is so specific?
- Her Mother died 2 weeks ago at Pineridge ALF- She visited frequently. Because she was private pay, it enabled her to have her Mom in a "nice" place. There have to be people or groups that will be active participants in the care beyond the care of the facility

employees. Feels that people 'outside' of a facility need to provide supervision for the PWD that is living in a facility. Family involvement is critical – there aren't enough family members visiting.

- Represents Manor Care – skilled nursing setting is reverting to a rehab setting. Increased challenges when PWD suffers an acute event requiring hospitalization. It is then very difficult to find appropriate rehab setting and funding is a huge barrier. Those on Medicaid – funding is not there to provide patient centered approach that's needed, especially with PWDs. AD is not considered a behavioral health issue.
- There's a lack of connection in the community that links people to resources. Develop a strategy for education and resource by creating a model that incentivizes the connection. Focus on outreach to diverse cultures needs improvement.
- Her Nana has had AD for 9 years. Initially they thought it was her HOH causing the repeated questions. She is not in a secured unit. The caregiver to patient ratio needs to be smaller. Because of the high ratio, odd things happen that shouldn't otherwise happen. There are safe guards with a decreased ratio which will prevent the negative situations.... i.e. Nana drinking shampoo.
- Elders are diagnosed with AD only to find out they've got severe depression and really do not actually have dementia. Has seen PWD get truly treated for depression properly and then the diagnosis of dementia was dropped. Physicians need more education. Vulnerable adults living alone promotes the gate keeper program which was developed in 1978. The more impaired we become as humane being the less likely we are to reach out. Gatekeepers started with postal workers, bank tellers, meter readers to promote or provide elder services with referrals for people appearing to become impaired. Elder services would then reach out and visit. It is one incident at a time, there's no solid system in place to be assured that no one falls through the cracks.
- Confirms that there needs to be a system especially when it is a situation where an ALF refuses to take them back either after an incident or a hospitalization.

Tribes

- For next tribal meeting, is there any tribal-specific data re: dementia?
- It is critical that there be representatives from the tribal health system. Tribal health services and social services addresses the needs of tribal community members. She discussed the timelines and opportunities between July and September for more tribal input. Tribal representatives should join the workgroup.
- HH volunteered to participate with the LTSS workgroup. She will send contact info.

Lacey

- I am a clinical psychologist formerly with the Dept of Corrections, as well as former clinical director of a large medical organization with long term care facilities. 2 issues: 1) dementia related issues are largely ignored in the correctional system and this needs to be addressed. PWDs with dementia in prison can be abused and neglected. 2) Long term facilities – staff should have been well-trained but were not; resulted in patients being mishandled as well as inappropriate use of antipsychotic drugs. Long term care staff needs to be better trained.

- This is hitting on many issues that I have endured. One of them is not being able to qualify for any assistance without spending down life savings. Went thru \$100K in 18 months. There are not many places to go in Olympia as far as facilities. The facilities her husband was in could not handle him. Moved him three times; the third facility had poorly trained and overworked staff. My out of pocket costs even with my husband in the facility were high; I had to purchase things like Depends and Ensure because the facility did not provide them. Re: doctor visits – my husband would refuse to go to his doctor “because there was nothing wrong with him”. It was a very challenging situation.
- Caregiver; husband has vascular dementia. Appreciates caregiver support programs such as having help with housework. Another important thing is to get physicians comfortable with making an early diagnosis, and talking about the diagnosis. It needs to be as easy to talk about dementia as it is to talk about a cold.
- People go into denial when they are diagnosed. I am having a lot of challenges with my mother. Safety is an issue; I know of someone who burned their house down. Smoke alarms should be connected directly to local fire department. People look fine and we tend to forget that their mental capacity is compromised.
- My mother was recently diagnosed. Asking on behalf of a friend: difficulty of applying for services; submitting the exact same paperwork multiple times. Need a ‘one stop shop’ and/or ombudsman to help people navigate the system. A: Unfortunate that some people have to apply for help more than once. We know it’s a problem and we are working on it. Affordable Care Act has added another layer to the process. Jerry Reilly: Re – ombudsman. The role of the LTC Ombudsman in WA is facilities. We need a different kind of ombudsman in Washington for the general public.
- How many state legislators are actually friendly toward the elderly/inclined to act on behalf of this population? A: We have emerging champions in the legislature. Joint committee on Aging. Karen Keiser and Steve Tharinger are both members of the ADWG. A: WA has one of the best long term services and supports systems in the country thanks in part to the work of the Area Agencies on Aging but also thanks to the support of the state legislature. It’s been tough the past 6-8 years because of state revenue problems but the commitment is there. A: If you have the opportunity, especially when they are not in session, to meet with your representative-that would make a big difference. A: Most of today’s panelists are members of the Aging Caucus; they stay on top of legislation relating to seniors and have introduced a number of bills including the enabling legislation for the Alzheimer’s State Plan.
- Grew up with a mother who was bipolar. Where is the distinction between mental illness and dementia? Is there a way to get early diagnosis? Looking for ‘magic bullet’. Somehow the state plan needs to address the difference between dementia and other types of mental illness. A: There is a great deal not known about Alzheimer’s. Tools for detection and diagnosis continue to improve but people are still challenged to find and access the right resources for accurate diagnosis. The issues surrounding the conjunction of dementia and mental illness are complicated, as are (to a lesser extent) the issues surrounding the conjunction of Alzheimer’s and other dementias. There are

probably over 70 different kinds of dementia, but Alzheimer's is the most prevalent. Some patients have more than one form of dementia. Parkinsonian dementia is becoming more prevalent. One of the things that we have heard at nearly every listening session is the need for two things: 1) some kind of road map or place where someone can go to get information that will make it easier for them to navigate the process; 2) more emphasis on effective coordination of care. A: From a publicly funded perspective, working on 'enhanced care' facilities. Expect to see more of these in the private sector as well. We need to get better at early diagnosis as well as better care coordination.

- Things families need: 1) knowledge, 2) tools and techniques; 3) energy; 4) navigators to help families get through it; and 5) financing. Most people don't qualify for Medicaid and have to spend down to poverty level to qualify. Also we need to look at people who don't 'fit' the typical profile(s), such as people in correctional facilities or people who don't have a family to support them. Legislators need our support – they don't have the 'elbow room' they need to generate the revenue to put the necessary things in place to meet this looming crisis. It's hard to close that gap. The plan needs a 'public campaign' component around generating revenue to pay for the plan recommendations.
- I have been advocating for six years for changing guardianship laws in WA. In Sept 2013 Gov Inslee held an aging summit; two recommendations. I have a GAO report from 2010 re: what investigators found in this state. Examples of abuse. What I am working on right now – guardians are charging excessive fees. \$750K, \$500K. Sen. Rivers from Vancouver introduced a bill regarding guardian fees; Law and Justice Committee refused to hold hearings on it. Seniors are being isolated from family members and friends due to guardians. I am here to ask for help in preventing elder abuse by guardians. A: Has heard about this issue in a variety of places; it seems to be appropriate to address in the state plan. It would be nice if the plan could speak to what our guardian system needs to do to serve elders and PWDs. Response: Sometimes the best solution is something other than a guardianship – we need to look at other options.

Virtual

- My mother, grandmother & great-grandmother all had dementia, likely Alzheimer's. Hoping state strategy helps directs us next generation on how to prevent, prolong, deal with Alzheimer's.
- Public posting of AD studies and how to volunteer as participant are important to me.
- To piggy-back off of what others said this is also a huge impact of family and children. Often times they become their parents IP's or caregivers. Meaning they get paid for only a small portion of time/money they are spending helping their parents. From driving them to appointments or caring for them 24/7. They obviously want to help their parents but often the cost is too great for them as well. We need to lean towards a 'treatment' to assist both the person and their family.
- I am only a student but in my time of working within Elder Services specifically the COPES program I see the services intervene once they are at rock bottom financially. If

we had something more preventively before it becomes desperate it would take a big burden off the family. This is more in terms of the financial point of view.

Sequim

- My wife was diagnosed in May '07. Took care of her at home for 3 years and 3 months, but it got to be too much work. She was moved into Discovery Care for 3 years before she passed. There are a few major problems: 1: Falls and restraint laws. Told by DSHS, that she had to be allowed to fall. Could have a wheelchair, but had to demonstrate ability to get out of it which he found strange. He understands why the laws are in place, but he believes the laws have gone too far. Wrote a letter proposing a restraint program that might lead to a change in restraint law (letter is attached). 2: Improper hygiene. Wife passed due to UTI. Caregiver turnover and nursing staff turnover could be to blame. Paying caregivers more could solve the problem, but is also tougher on the family.
- Mother had Alzheimer's the last 8 years of her life. She became a volunteer for the Alzheimer's Association. First issue is the financials for people who cannot afford respite care or in home care. Second issue is with reaction time of those with dementia. For some reason individuals with dementia are passing driving tests and families don't know what to do about it. Could we implement a reaction time portion into the driving test? Third issue is with the lack of updated training for health care professionals working with those with dementia. Sometimes the lack of updated training makes them forget to treat people with dementia like actual human beings.
- Has heard geriatric doctors talk about the use of the "A" word. Feels that we need to press those in the medical community to be straightforward with patients and families about diagnosis. Giving the actual diagnosis earlier can help slow progression and help families prepare for the future. Here in Sequim we think of ourselves as a community of old people and their parents, so we need to work together on a more coordinated strategy to approach this and help.
- Is mother with Alzheimer's primary caregiver. Took facilitator training from the Alzheimer's Association and would recommend it for everyone. There are so many people that are looking for a group and there is a shortage of facilitators here, so she believes that making of facilitator training more accessible. Personally, she came to Seattle for a few days which can be costly and limits who can do training. Bob Le Roy - Thank you for your commitment to be so involved as a facilitator. We agree, there is need everywhere! We would like to create more groups because we have over 200 on waiting lists to get into groups, but we struggle to find volunteers that are willing to make the commitment. If we were to find more people in a community, we could bring out a group, but there is a struggle to find more. Suzie – The Association has strict rules on who can and cannot be a facilitator which she feels could be eased because it is eliminating potentially good candidates.
- Member of Port Angeles Caregivers Group for a very long time. Aware of the rising cost of institutionalized care while there is a growing shortage of independent caregivers. Feels that we could help ease this problem with: tapping into the unemployment group (with proper background check), asking the Employment Agency of WA to attend these

meetings, contacting Peninsula College, and approaching dropouts of from nursing school that can't pass organic chemistry. - A: WA is a leader in homecare in age and place – so folks can stay in their homes where they will be healthier and happier. But, as Howard mentioned, there are some challenges with wages, turnover, and training. I think we are making progress, there are caregiver programs (SEIU has raised caregiving to a profession). In the budget discussions it is very clear that the client is happier at home so we are pushing that way. A: When I started with this group came as a representative of a nursing school. Course work can be so demanding that students can't get involved. My school had a Community Health Clinical and program where one student was partnered with one elder heart patient for 2.5 years. Pairings could work for students, potentially with one or multiple people. When students came in very few were interested in elder care, but the pairing helps them get to know and love a patient and become more excited about elder care.

- Full-time caregiver for my wife. She had the same doctor for 16 years that said she was just aging and did not have Alzheimer's. When wife was finally taken to a new doctor, the doctor immediately recognized that wife had Alzheimer's and a heart murmur. Allen was put on 100% disability so he could not get hired anywhere which has made finances tight.
- Caregiver for a father with Alzheimer's and demented mother. The two issues that concern her are legal limbo and surviving spouses. Had issues getting the legal powers that she needed and it put father at risk – father was still able to drive and almost burnt house down, but there was nothing she could do legally. Her concern with surviving spouses is wondering how to take care of them financially since Alzheimer's is such an expensive disease. Legislative initiatives for stop loss so spouses won't be poverty stricken? A: Those are two challenging issues that you have raised. The guardianship issues: chair of judiciary committee in leg. This is on the list of things to address for our committee. Looking at some way of establishing control through legal system. Apparently there are states that have legislation that have laws that guide this. It is important and part of our work plan. Surviving spouses is also an issue that we tried to address in our first few years as a committee but it is a federal issue. It is a challenge to get things done, but again it is on our screen.
- Tired of hearing "Oh, we are working on it." Wants to see real actions. Encourages everyone to be as noisy as possible and keep bugging their government officials. There needs to be, even if incremental, progress. A: On guardianship, we are really working on that and it will change. The other things are budget issues and that's the challenge in Olympia. Our budget in house, democratic budget, looking to increase revenue by 1.2 bill. Republicans will say that we don't need additional revenue to meet our obligations. If you drill into that statement we set rates for hospitals, etc. you then have obligation to meet that salary. This additional \$3 billion revenue coming in is eaten up to meet our obligations. The relationship between patient and caregiver is so important, but if someone is working at minimum wage they can't take care of their own family let alone another patient. There is a stipulation in our bill to provide pension for in-home caregivers. The senate republicans don't want to support that – not having that piece also makes that job unattractive. Working on the 9% increase in our budget just isn't

true. It is more than talking about numbers, it is talking about what kind of state you want to live in and how are we going to make that happen. Instead of hammering everything down, look at different tools. Washington is the most regressive state tax wise – sales tax on internet sales. We lose \$450 million a year. If we could close that we could go far getting budget fixed. The decision on internet sales was made when internet sales were minute, but now they are massive. In WA House Democrats have proposed a nexus for internet sales. If you have physical presence then you have to pay sales tax. Proposing to expand that if you click on your computer you pay the sales tax in that state. Could generate \$90 mill for WA per year. One of two states that don't exempt bottled water, if closed we would generate another \$60 mill. Point: there are other options for creating revenue.

- Husband lives in home for those with Alzheimer's. He had complete access to his thermostat and turned it on to very hot. He fell between toilet and heater – got 2nd degree burns. Facility claimed that they max the thermostats out at 72 degrees, but clearly wasn't true. No report was ever filed. She would like nursing homes to be more regimented – specifically those places for people with Alzheimer's.

What would make a difference in getting a diagnosis?

Yakima

- Could the Alz website have a list of docs who are trained in diagnosing and follow-up for dementia? - take out the guesswork in finding a doctor. A website/portal. Is there a certification in dementia diagnosis/dementia care?
- Is there a way to impact medical schools' curriculum on Alzheimer's and dementia?
- Earlier diagnosis would help family members to plan and prepare; possibly increase ability for PWDs to get into trials.
- Get rid of stigma – people don't get dementia because they did something bad.
- Recent Guidepost article about Kim and Glen Campbell – recommended reading.

Seattle

- Before becoming a Care Consultant at the Alzheimer's Association, he worked on the diagnosing end, under a neuropsychologist. Having the primary care docs make a referral to neurologists. Docs are not taking the patients seriously, not referring, or just throwing medications at the patient. A big part of his current job is to make sure that patients have been referred appropriately and are getting appropriate care. Provider education is key, including when they are in training to get their licenses as well as continuing education.
- I'm connected to someone with Alzheimer's. Recently had a fall; first responders did not ask if a family member would ride in the ambulance with him to help keep him calm. They strapped him down in the ambulance; he was very agitated and ended up getting dosed with sedatives upon arrival at the emergency room. It could have been avoided if family could have gone with him in the ambulance. Paramedics need training on how to properly deal with PWDs in emergency situations.
- Was able to get a neuropsychologist to evaluate a client and was found to be developing dementia. However it was extremely difficult to communicate the diagnosis with the

patient. When Alzheimer's Association finds someone "our people", (I assume she means a person who is deaf/hard of hearing), they need to know where to reach out for the appropriate resources for hard of hearing people.

- People facing cognitive decline are scared. People need the Alzheimer's Association/other resources. How to make the healthcare relationship better: people sometimes need advocates. Whether it's to help overcome barriers of non-English speaking, hard of hearing, dementia; advocates need to be part of the system.
- Diagnosis process was really frustrating. Went to PCP; he sent them to "experts" who weren't helpful. Counting backwards, backwards alphabet, questions he could not answer. At end of assessment, they said "We don't see any problem". He went to another doc and got an MRI; "yes there is a problem" but they couldn't say what it was. Went to yet another doctor and asked for a referral to someone who understands Alzheimer's. They did tests and then sent him to Harborview for further tests. At that point the dementia was diagnosed. "Our biggest problem right now is, 'Where do we go from here?' It's very frustrating."
- Training police and fire departments is crucial, as well as training physicians.

Spokane

- De-stigmatize AD
- Testing takes 2 – 4 hours – example: PWD had to use the bathroom & just left the testing; so make the testing shorter
- Physicians need to still be an important role even though they can't "do anything" for this disease
- We are losing MDs, there are fewer Geriatricians, so how can we get enough skilled adequate diagnosticians?
- Time – the MDs need more of it to spend with these families
- Would like an MD to refer families to something, somewhere or to at least provide them with brochures at time of diagnosis

Tribes

- Within our medical system, our medical providers have not received training on aging diseases.
- On average tribal members have lower longevity than majority population.
- Although tribal members are living longer, tribes do not have the training, resources or info on LTSS so they would have to rely on resources outside the tribal resources
- People have had to leave tribal communities to receive needed services which is a hardship on the individuals and their families.
- Tribal researcher out of University of Wisconsin Dr. Neil Henderson, related to dementia specific to tribal members but that was 8-10 years ago.
- ADWG should see if they can find that research NWRC has specific funding connecting their tribe to the researcher. Shelley may have the info.
- Need screening tool that doctors can use and tribes can use and bill for.
- Do we have demographics specific to Alzheimer's re: Indian Country?
- Seeing prevalence of depression and MH issues in their elders.

- Drug/alcohol issues and treatment of geriatric patients.
- Life expectancy is lower in Indian Country, so this is a newer issue to address. This is a new horizon for tribes to address, and is a growing concern.
- Seeing social workers and education and training lacking.
- Alzheimer's/dementia linked with spirituality and life experiences.

Lacey

- This needs to start in medical schools; they need to keep up with the changing demographics in our population. More focus on geriatrics.
- You need to go to a general practitioner and get a referral before you can even get to a neurologist; not every GP wants to refer. A lot of steps to get to a diagnosis.
- Still don't know if my dad has a diagnosis. I don't know what my parents are going through.
- There needs to be an Alzheimer's hotline.

Virtual

- Some doctors seem unwilling to do the testing and evaluation.
- If doctors could encourage their patient to bring family member or friend with them just to make certain all the information is understood. My mother's doctor had trouble telling a long time patient ... and she wouldn't have heard it until I came in. Doctors should suggest it.

Sequim

- Family input. For her dad, wife covered for him – she answered questions for him. Doctor had such a longstanding relationship with the couple that he didn't care if wife intervened. Doctor seeing patient on own could help.
- Gerontologist also a doctor. Have to change culture of training for physicians and other caregivers. It isn't just local issue – it is a national issue. Once we begin to educate medical professionals that older people are humans and deserve equal healthcare. Have to work with medical associations and medical workers as well.
- Husband is RN in long-term care facility. She is caregiver to grandma who has been diagnosed with dementia. Getting a diagnosis comes down to discerning between old persons issue and seeing this as a disease. Starts with training of physicians and continuing support.
- Father-in-law had early onset – first symptoms came on in his 50s, but mother sheltered him and hid him from diagnosis. Have gotten no information from doctors as concerned children which could have helped.

How can we make health care better for people with dementia?

Yakima - none

Seattle - none

Spokane

- De-stigmatize AD

- House doctors need to respond more quickly in special “in-house” calls, time is of the essence
- It’s not just family practitioner MDs that need education but the specialists like eye doctors, dermatologists, and dentists ALL physicians need the information & training because PWDs visit a variety of doctors just like the general public
- Have MDs connect families with research studies so that the family feels good about getting the diagnosis and information from > one source
- Do everything you can to improve PWD’s senses i.e., best possible input for the brain leads to the best possible output. MDs should consider that during the visit. Perhaps instructing or informing the family of such.

Tribes

- Many tribal members didn’t link chronic conditions and difficulties. This is an individual experience, and complications with aging exist.
- I have a sister with dementia. She suggested Indian Health Services and AAA would be the best place for tribal members to get information about Alzheimer’s. In her sister’s case, her Indian Health doctor didn’t have the proper training to diagnose the disease and educate the family.
- Suggest reaching out to community health workers, put information into tribal newsletters, and participate in tribal health fairs.
- Individuals may be experiencing issues but there is a reluctance to talk to health care providers about it so people continue to struggle without appropriate information or diagnosis.
- Dementia exists, but it is unspoken. Caregivers and family members can use help, but won’t share diagnosis with community or extended family. There are issues around lack of openness to discuss info about diagnosis.
- In addition to stigma, there is fear in having to leave home and reservation to go into a care facility for short or long term.
- There is also a significant lack of treatment for mental health issues for geriatric patients.
- The research report referenced earlier included specific recommendations targeted to tribal populations. We need a specific section in the plan that addresses American Indian/Alaska Native populations.
- Things have to be specific for American Indian/Alaska Native populations.

Lacey

- People don’t take medication – there needs to be some kind of monitoring system instead of depending on people who are in denial. A: We have been working to design technologies that can monitor the use of medications as well as other things. Tracking pills etc. The issue – is this something that your family/mother would welcome – this kind of “intrusion”. Participant: I want my sister to monitor. Caregiver should monitor and if patient is refusing meds, report to case manager. As far as technology – this is a ‘gray area’. But do not rely on the person with dementia to manage their medication. No new prescriptions until current supply has been taken.

- Some kind of benchmark in terms of observing memory loss that triggers further intervention.
- Give people videos that they can watch that will give information both at diagnosis and as the disease progresses. Also – education needs to start in high school, not in medical school.

Virtual - None

Sequim

- Too many situations where caregivers aren't consulted. Decisions should be run by them. Educate providers about HIPA laws that seem to be taken too far.
- Family has to be much more involved. HIPA laws have caused some extreme disadvantages. Working with a group here in Sequim, part of Eden project, to change the culture in healthcare facilities.
- There has been an increase in number of people who have insurance through ACA. Providers have become maxed out – takes weeks to see someone unless emergency. Grandma fell and waited 8 hours in ER with potential broken hip.
- Regular appointments should include some sort of mental status exam. Just a few easy minutes that is recorded and done consistently. In Massachusetts there was a big push in healthcare systems for victims of domestic violence be identified – every time I saw anyone I was asked if I was alright. That could be a great program to implement here. - A: There is something in Medicare called 'Annual Wellness visit' where they are supposed to do a mental health screening. Only nationally 1 in 6 people are actually doing it. People are learning about it, but it is slow. There are tools available, we just need to teach people to utilize them.

What keeps families from reaching out for help early on?

Yakima

- Not knowing that help was available
- Being too overwhelmed or too busy to ask/search; when doc didn't have info or does not refer, there was an assumption that nothing was available.
- Docs that won't refer out; they want to 'do it all themselves'.
- Ability to get second opinions/seek out a neurologist? - depends on insurance; usually need an approval from PCP or insurance first.
- At the point of need, having some kind of a navigator would be helpful.
- Financial considerations – e.g. that might prevent families from bring in caregiving help.
- Privacy concerns.
- Stigma.
- Fear of the unknown.
- People don't recognize that they have become caregivers.
- Cognitive/behavioral change – denial, resistance of the care receiver to get help because they are cognitively impaired and/or embarrassed.

Seattle

- Lifespan Respite Washington. We are running a pilot project; what I'm hearing from caregivers is that they are exhausted and they feel like they are going crazy. Looking for long term respite. Many say they can't afford co-pays for respite. It's important to look for supports that are not just income-based. Also the process for applying is too "intrusive".
- United Way of King Co. Worked with AAAs on a 'caregiver module'. Barrier – people not seeing/identifying themselves as a caregiver. By the time they reach out for help, they are overwhelmed. Barriers of individual capacity to look for resources in the face of being a full time caregiver. How do we make resources easier to access?
- Denial (it's a survival mechanism).
- For some deaf families – they may have raised their children and have come to depend on them for so long that the children are burned out and don't want to have anything to do with their parents. Ask that the working group address "deaf-friendly" caregivers. Look at definition of family; in deaf families the communication may not be strong and relationships may not be strong.
- What keeps families from reaching out for help early is A) stigma and B) not knowing what resources are available due to not getting information at the time of diagnosis. We need physician education and helping providers to understand where to refer people. One of the best-kept secrets is the Alz Association; the Assn has been providing services to persons with early stage memory loss for over 20 years. There is an Early Stage Forum coming up soon and a lot of people don't know about it.
- Look at early gatekeepers; change their behaviors. Also not just look at changing other people's behaviors (gatekeepers) but also work to connect with the public ourselves. Public service announcements.

Spokane

- Feeling inundated and overwhelmed. They need a "to do" list i.e. Legal & Financial, etc.
- Stigma & guilt for reaching out for help. They feel poorly that they don't know how to take care of their loved one's needs any longer.
- Denial of siblings & children of the problems increases stress of the spouse.
- With knowledge comes acceptance so increase the education
- Family members need to put themselves in the PWD's position because it's doubly hard on the PWD.
- Fear we're going to take away their control... especially in men. Suicide and homicide is in greater in male elders

Tribes

- The friends and relatives have difficulty knowing how to approach the elder with dementia. The change in roles from mentor, teacher, or guide is very difficult to navigate. Caregivers need a safe place to grieve the loss of previous roles the elder held.
- Having an outsider come in to the community to do an assessment for an individual can be a barrier.

Lacey

- Stigma attached to dementia. May be related to the fact that it can't be cured (unlike cancer).

Virtual

- I reached out early but Area Aging & AD groups focused more on those living with the affected person. I couldn't. I had to work. I needed help from that perspective. (And help for me if I need it will likely also need that.)
- I feel that the main barrier is simply the overwhelming future that get put in from of them once they hear the diagnosis.
- Help on how to find and monitor inpatient care. How to help find somebody to cover finances of the single person (no kids or family) with AD.
- Macho man theory I can take care of her, I am the man.

Sequim

- Independent people who don't reach out for help because of the stigma. Afraid of friends and family disappearing because they don't know how to handle it. If there was some way to teach caregiver to say "How are you?" and "What can I do to help?" that would be very beneficial. Support groups are quite beneficial for this as well. We have volunteer county service in helping people care for little ones. Could implement for people with Alzheimer's – read a book to patient and let wife go shop. This needs to be a community understanding because this isn't a heart problem that we know all about. It is going to affect everyone in a small community, so we all need to be educated and publicity of support groups.
- Obviously information is important, but what would be helpful on a broader scale would be a reduction of negative stigma. Social marketing campaign that would make people more comfortable talking about this disease. The loss of cognitive function can bring a sense of shame, but people need to support them and tell them that we still honor and value them.
- People can rely too heavily on church so provide alternative support groups. Transportation for people is key to continuing a social life and keeping up with regular tasks.

What information, skills or services are families looking for?

Yakima

- Good referrals
- Better understanding of pharmaceutical options
- Self-analysis (seeing/recognizing signs in oneself)

Seattle

- Care Consultant with Alzheimer's Association. Respite is a huge need. Caregivers can't access support if they can't leave their care receiver alone.
- (Asian Counseling Svcs): Language barriers are a problem. At her organization, case managers are bilingual. Empowering organizations who can speak the languages (like community health centers) to provide supports and referrals.

- Has a friend who has been a caregiver to her husband for 15 years. Got respite care that was 75% paid for, and was able to leave her husband for two weeks, but the funding went away.
- Was a long distance caregiver for his sister in CA – learning to navigate the system long distance was challenging. The older that people get, the more reluctant they are to try to navigate the system. Look at communities such as faith-based communities for support. Primarily, people need to learn to advocate in an assertive and proactive way.

Spokane

- ADPs
- Memory Cafes
- Places to go without the stigma, like in Europe where they have normalized environments
- Pragmatic approaches – places or educational tracts that provide tactics & skills -Family Training.
- Provider Training in how to care for dementia

Tribes

- In Indian Country, people want to stay in tribal homes with tribal caregivers.
- It needs to be easier to become an individual provider.
- We need to take care with language. Rather than “How do we deal with this disease”, use “How do we live with Alzheimer’s and dementia”. This approach with caregivers helps them see there can be productivity for individuals with dementia. Help caregivers not just with respite, but also with language and attitude supports.
- When sister got sick, her two brothers stepped back and left all the responsibility for decision making and caregiving to the sisters.
- Need for education and outreach to primary care providers. Does ACL have specific developed materials for tribal populations related to Alzheimer’s resources?
- Use of language is very important to maintain a person’s dignity.
- We need training closer to home.

Lacey - None

Virtual

- Help families know how / when to reach out for hospice care which was so helpful.
- I think building a community around this disease is very important for the family. The community includes trained and understanding individuals, opportunities for families and patients to socialize, Alzheimer’s cafes, etc. My mother had early onset dementia and I only began to enjoy my time with her when I changed MY mind and perspective. To live in the moment with her and not let my version of normal life and how things SHOULD be, be the only way they could be.

Sequim

- When wife was diagnosed they had no idea where to turn. It would have been helpful if there had been a person that could have sat down with me and helped lay out a plan.

Do you have suggestions for how to better support family caregivers?

Yakima

- Better TCARE Assessment – covers physical supports; weak on mental/financial. 3 hours a day of caregiver assistance when she takes care of her mom 24/7.
- For people who are financially able, do they go to AAAs for information and assistance?
-- Yes.
- Homecare – help with bathing/toileting etc. Very costly (\$25-\$35 per hour). So had to rely on family for that help. At end stage it took 2 people to bathe the care receiver.
- Finances. If you don't qualify for Medicaid, care assistance is out of reach.

Seattle - None

Spokane

- Faith based organizations to be involved because people take messages from people they trust more readily
- Government needs to understand that we save lots of money \$\$ by keeping people at home longer. Get Medicare to pay for ADPs
- Develop Memory Cafes
- Develop a system where the PWD can't leave but is also not confined... similar to the place they have in the Netherlands, so as to give them a sense of home and community.

Lacey

- 6 of 7 of my siblings want mom in nursing home; one sibling says "no". Mom is in Korea. The 6 siblings need to support the 7th (the one who is the primary caregiver). Respite. Caregivers need care.
- Families don't always give the primary caregiver adequate support. What are caregivers supposed to do when their families refuse to help? This happens more often than a lot of people realize.

Virtual

- Maybe employers of folks with AD family members need to understand need to take time off for the "AD cafe" or other planned socializing activities, not just the medical emergency leave. My employer probably would have allowed it, but I didn't even think to ask.
- Respite and counseling for family caregivers.
- If there are "informal caregivers" (friends, neighbors) who wouldn't charge or charge less, there would need to be some type of oversight (again I'm thinking if I get there I may well be alone ... so somebody needs to be watching out for me).

Sequim

- What would have been beneficial would have been a consult bank – voucher system that gave me a free hour of legal support, or an hour with doctor outside of a regular appointment. Let caregivers pick and choose from buffet of resources.

What specific care supports would help to allow a person to stay at home longer?

Yakima

- Funding to expand care and get rid of waiting lists. FCSP could help if they could reach more people.
- Personal care assistance funding.
- Caregiver respite.
- Support groups and education for caregivers.
- Beefing up transportation services, especially for rural areas.
- Get financial support to people who need it.
- Alzheimer's website has been helpful. Paperwork done online for service eligibility.
- Groups of doctors that get together? Medical associations – make contact, make presentations to doctors.
- More money from pharmaceutical companies; they are making a lot of money from Alzheimer's.
- Chicken or egg with big pharma because right now there is no drug.
- Don't underestimate the power that you have as members of the community. Alzheimer's Assn asked their support group participants to go to their doctors with information; since doing that, number of inquiries from docs has increased.

Seattle

- Her parents belonged to Kaiser in Oregon; father had health issues and hearing loss, mother had vision and hearing issues. She found people at Kaiser to be helpful; assigned a social worker to their cases; physician was a gerontologist; she felt like a partner. The distance was a problem so she had to depend on the system for support, and the system that Kaiser set up worked for her.
- Somehow work with universities to get credit for students to provide care as a way of helping with cost.
- Educating the community about dementia. It's hard to convince people like family and friends that we have a problem that we are working through. People visit for a few hours and don't think they see a problem. There is info on the Alzheimer's website that talks about that, but not much.
- Supporting a friend who is a caregiver. She helps them with technology. Technology can be very difficult for older people. Need to be able to select the right devices, ask the right questions. People in their 80s and 90s may not know how to use a cell phone or how to retrieve a message off of a phone.
- Affording a caregiver when you have a moderate income. People don't purchase long term care insurance. A: Unfortunately, long term care insurance is getting harder and

harder to find. Participant: her mom has a policy and it's great, but you can't find it anymore. Q: Could the state offer long term care insurance?

Spokane

- Educate yourself about what is available and then see someone to help you. Advance planning is key. Anyone should become qualified to get things that are owed to them: Washingtonlawhelp.org
- Visiting and attorney or the VA can be confusing because there's no one specific advisor to go to. So develop specialists in the field that families can be directed to for practical advice.
- Increased awareness by everyone of the situations
- Weekly nurse visits to assess if a PWD who lives alone is doing what they're supposed to do regarding their DALs & meds
- Respite! ADPs! And/or non-medical in home care

Lacey

- What's available for people like me? I asked for help from my siblings and they would have nothing to do with it. My parents needed to talk to me about their financial resources, but they didn't until it was too late. I had a guardian involved who put my mom into a facility against her will.
- FCSP reaches about 1% of caregivers. Respite is important to give caregivers a break so they can maintain the energy to stick with it. Little things like help with housework and errands. The family dynamic is important. Some families hang together, some don't. There is a need for counseling at the point of diagnosis. Much bigger investment in FCSP is needed. When families fail, patients 'skid' into the public system; it behooves us to support the families and see that they don't fail.

Virtual

- Long-term care planning and long-term care insurance was the only thing that kept my mom from financially draining my dad. Although we had to fight with the insurance company to cover certain things. It wasn't an easy road, but it was worth it financially.
- One of biggest helps with hospice is that 911 (& ambulance costs & hospital stress) didn't have to happen with every fall. I wish that AD care facilities had more leeway.
- Get DOL to help with notices about dementia and voluntarily giving up driving!
- Make not driving a cool deal! I want to give it up before I have to give it up.
- My mother had end of life directives and that didn't stop having to go to hospital after falls.
- So have state laws allow for more detailed directives.
- What about a cadre of volunteer teenagers or senior citizens to take the patient to appointments and trips?

Sequim

- With veterans, through veteran organization, helping transport them to and from appointments or grocery store to help allow them to stay at home. Try it for people with dementias. Also trying to get a system of babysitting for elderly to give the caregiver time to relax and patient time to think about something else.

- I would like to see an expansion of day programs. Socialization is so important and can be lost if home with just one caregiver all of the time. If they wonder or have incontinence issue they are often turned away from day programs – maybe that is something we could fix.
- Motorhome is solution for wife to relax and not having accidents in other places. Can still go places, but we have a way for her to always be taken care of.
- Olympic Area Agency on Aging, people often call in saying that loved one with Alzheimer's refuses treatment or care. If we could get doctors to do home visits it would really help.
- For mother, having a place to go for respite care was troublesome because would not get in car. Have to try to trick or lie to mother to get her to go to doctor to prevent UTI. Doctor home visits would be nice.
- Caregivers aren't trained well enough. Males take care of females which can be issue due to lack of knowledge. I think that there should be another critical issue: what to do when taking care of someone at home becomes too difficult. Helping with transitions: both helping people plan and helping through support.

What are some realistic suggestions for providing help with care costs?

Yakima

- My mom's home is paid for. Just has utilities and groceries. Daughter helps. Should you sell the home and put the money into an account to take care of them? Put them into a small apartment or have them live with you?
- LTSS study in state of WA. Public/private options for long term services and supports? There has to be something at a federal level.
- There is money in both senate and house for this LTSS study. Only second state to undertake such a study for financing LTSS (other state is Hawaii).
- Ask for help from friends, church, community. Volunteers.
- Write a list of all the things you wish you could have help with; show it to people who ask if there is anything they can do.
- "Spending down to Medicaid" – and then having difficulty finding facilities that will accept Medicaid patients.

Seattle - None

Spokane

- Seek corporate sponsorship for the costs of offering safety services for those who cannot afford it
- VA: unless it's service related, they don't help – change that
- Public/private partnerships to provide in home support
- Trainings for both family & professional caregivers to provide consistency of care

Lacey

- Long term care insurance is "too damn expensive". It's our own responsibility to take care of ourselves when we get old. Not everyone has a caring daughter. My wife and I

have tried to do long term planning and everyone should do that. There need to be policies to ensure that people set aside money from their paychecks for the future. A: Part of the idea of LTSS financing study is to look at sustainable programming. Maybe it looks like Medicare or maybe it's a payroll tax to fund it.

Virtual - None

Sequim

- After 3 years, employer no longer is paying what is associated with that injury – the state starts to pay for that injury. Tax payers have to.

What specific help do people with dementia and families need?

Yakima – None

Seattle – None

Spokane

- Chore services: like meal prep, taking out trash, yard services etc.
- Legislation to intervene earlier. There are laws to protect animals but not elderly. Ways to promote giving up driving earlier
- Support groups & ways to get the information TO the family about them
- Knowing PWD likes/dislikes & knowing their history for caregiving ease
- More info on musical response that's meaningful to the PWD. Getting a good history.
- Respite due to overwhelming nature of caregiving

Lacey - None

Virtual

- Thank you for doing this work for all of us. I will continue to follow the strategy and how I can help, others and myself.
- Local support group opened my eyes and helped me understand my feelings
- I have been in the past. My mother died in 2008, but I do have a good friend with a good friend who has AD so I will let her know about next Tuesday's meeting in Olympia.
- I'm planning for retirement soon, but planning for the potential for AD is important also and you helped put it on my "when I retire list" of things to do! Thank you.

Sequim - None

What help do people with dementia and their families need with respect to safety and behavior challenges?

Yakima

- Constant supervision of PWD – exhausts the families. 12 or more hours per day, 24 hours if the PWD wanders at night.
- Home safety evaluation – available to Medicare patients. Might be available thru private health insurance – depends on the plan. You can ask for a referral from your physician for this, from a physical or occupational therapist. Yakima AAA offers free evals from a durable medical equipment company.
- Monitors, pill minders, assistive technology – but they cost.

- Families need to know what to expect. Pre-education.
- YouTube videos for family caregivers – helpful hints etc.

Seattle

- Home health services provided through Medicare – home safety evaluation and outfitting homes. People need to have access to this service.
- Devices, some simple and inexpensive. Home health services under Medicare are fully paid for. In home mental health services, mental health staff who go to the home and work with caregivers on behavior management. Sometimes pharmaceutical treatment, not to sedate but to help with behavioral issues.
- Has an aging stepfather with Alzheimer's and a disabled father in Canada. Stepfather wears a medic alert bracelet as well as a second bracelet made by his wife to help responders understand communication barriers. Something that identifies health and safety issues specific to the PWD.
- Project Care Track via Snohomish County – radio signal bracelet. Silver Alert System (similar to Amber Alert – for vulnerable adults). A: there is a Silver Alert bill in the state legislature right now. Looks like it may pass.
- There are agencies out there that do not send out qualified sign language interpreters; be sure you are dealing with the right services.

Spokane

- The home as well as items in the home should be evaluated or assessed for safety i.e., rugs, door handles, medication storage, railings available, etc.

Tribes - None

Lacey

- He and his wife have been befriended by a Russian immigrant family who has taken them under their wing. This family sees to it that they have food on their table.
- Her sibling puts contact information into every pocket and purse that her mom owns, so that if she wanders and is found the authorities know how to contact. We have to acknowledge with parents that the roles are reversed as far as who is the caregiver and then address the safety concerns. A: Medic Alert Safe Return (both for PWD and for caregiver); There is also a GPS tool. Available at alzwa.org.
- How do we use new technology? Confronts issues of privacy and of choice. Also we need to think about other types of residential solutions. Think of "home" as how you live vs a specific location. How do we coordinate with first responders? They are the first to be called when someone goes missing. We need to challenge the norms that we have regarding things like choice. We need to understand that certain people may have fewer choices.
- Need to emphasize the services that are available for caregivers and how important it is for caregivers to utilize. 1) Alzheimer's Association; Alzheimer's Reading Room (created by a man who cared for his mother and who came up with many creative ways to address her behavior issues).

Virtual

- With behaviors, again, sometimes I think it works to change your perspective. Instead of getting frustrated when a guy I knew kept losing his wallet, his wife bought 6 wallets that all looked the same and when he got paranoid about losing it, she'd say "here it is!" and give him a new one and he'd immediately calm down. She could've stressed out with him, but she changed her perspective.

Sequim

- Asked senior group if there was anyone in the area that could do a safety inspection of his house. Need someone who was familiar with dementia that could help point out home safety instead of having to attempt researching alone.
- The best thing that ever happened to me was project lifesaver (<http://www.projectlifesaver.org/>). Husband was an avid walker who could have gotten lost. Go to police department, get a little bracelet, has GPS, police will change the batteries once a month, and it only costs \$50. Also, a burglar alarm that would go off if he tried to escape.
- Training for caregivers on falls– people don't realize what can cause them.

Any feedback about the national plan action items related to Native American populations? (Specific request of Tribal representatives)

Action 2.A.11: Strengthen the ability of primary care teams in Indian Country to meet the needs of people with dementia and their caregivers

HHS will expand awareness of care issues for Native Americans with AD and improve the dementia-capability of professional staff in Indian Country. The Indian Health Service (IHS) will use the Chief Medical Officer Rounds series, the IHS Primary Care Provider, and other existing trainings and meetings to disseminate information on ADRD.

(Updated) Action 2.C.3: Connect American Indian and Alaska Natives to Alzheimer's disease resources

ACL, IHS, and NIH will continue to coordinate efforts to improve the dissemination of information on dementia in Indian Country. ACL will publish materials on its website pertaining to funding and activities under Older Americans Act Title VI [<http://Olderindians.aoa.gov>]. HHS will continue work to improve dementia care among Native Americans through the NIA-sponsored ADCs. Alzheimer's disease will be raised as an issue among the trans-NIH Program Interest Group focused on Native American research and the trans-NIH American Indian and Alaska Native Health Communications and Information Work Group. HHS will disseminate information and increase access to resources for people with Alzheimer's disease and their caregivers adding links to relevant websites. Finally, ACL and IHS will collaborate to include resources for elders and families addressing Alzheimer's disease in the Resource Manual for the Older Americans Act Title VI programs, which serve Indian Country.

- Can the draft report that will be developed in May be a part of the June Money Follows the Person tribal meeting? Marietta will get with Alzheimer's group and report back at the next IPAC meeting.
- There was a request of Loni to send out the questions from the PPT to the entire distribution group for additional feedback.
- Perhaps there might be an opportunity to discuss plan at Fall Tribal/AAA meeting.
- Definitely include training and education about information and resources for primary care provider teams.
- Specific information for Native Americans.
- Review other state plans for ideas for specific action items that can be included in our plan.